

29 June 2009

The Honourable Tony Ryall
Minister of Health
Parliament Buildings
WELLINGTON

Dear Minister

Background to review

The Health and Disability Commissioner Act started in 1994 and the Code of Health and Disability Services Consumers' Rights in July 1996. The law tells the Commissioner to look into both the Act and the Code, decide if they need amending (changing) and report any possible changes to the Minister. I decided to look into both the Act and the Code at the same time.

Consultation (discussion)

In August 2008 I asked for first thoughts about the Act and the Code from some people and groups in the health and disability service sector to help me sort out any possible changes to the legislation. Thinking about what they said and adding my own thoughts about the Act and Code, I put out a discussion document and asked the public what they thought in November 2008. My discussion document talked about the key parts of the Act and Code and suggested things that might be changed.

Copies of my document were sent to a wide range of consumer and provider groups and agencies. A commentary about the review and a copy of my document were posted on the HDC website. I also held some meetings around New Zealand with various interest groups to talk through the issues.

I received 122 submissions, or pieces of feedback, as part of this review. Details of the discussion process and a list of those giving feedback are in the appendices to my report.

Report

Having read through and thought about all the feedback, and again thought about the Act and Code, I now give you my final report.

To keep the report short, I have listed the key issues raised and summarised the feedback about each issue.

I trust my report will help your thinking about possible changes in the Act and Code.

Yours sincerely

Ron Paterson
Health and Disability Commissioner

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KEY ISSUES

This is the third review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights. I think that the Act and Code are working well. However, I see three key issues that need to be fixed by changes to the Act or the Code. These three issues are summarised below.

I thank the Centre for Compassion in Healthcare for their campaign to add to the Code a right to be treated with compassion. I do not agree with this change because it does not fit with a disability view (in a Code that belongs to disability and health consumers). The Code already lets us discipline in law a provider for bad and uncaring behaviour. The very good wish for compassionate health care is better looked after by ethics and training than by rules in the law.

Disability

The discussions showed that many in the disability community want changes in the law to give more teeth to the rights of disability services consumers. Feedback made a strong case for the Commissioner to be able to make providers explain why they had not given disability services on time which a disability services consumer has been assessed as needing. This would be a simple and possible reform, protected by the needs assessment process. Clause 3 of the Code (the defence of "reasonable actions in the circumstances") covers shortages of resources. I think that the Act and Code should be amended (changed) as follows:

- change the meaning in the Act of "disability services consumer" to make sure it is in line with the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities;
- change the meaning in the Act of "disability services" to add needs assessment and service coordination services;
- change Right 4(3) of the Code to give disability services consumers the right to disability services that they have been assessed as needing after a needs assessment on time.

Advocacy services

Both the Director of Advocacy and I think that the current model for advocacy services is past its use-by date. Problems with how advocacy services are looked after include:

- the Director is not able to hire or supervise the way advocates work;
- wasteful use of resources; and
- it is hard to make sure an even quality of service is given across the country.

Most feedback supported change. I recommend the Act be changed to let advocates be staff in HDC, but still keep their tasks separate from those of the Commissioner.

Right to privacy

The most important thing left out of the Code is that it does not cover the right to privacy of health information. Yet the right to privacy is a key part of the quality of health and disability services and the rights of health and disability service consumers. Currently, consumers whose privacy complaint is a part of a service quality complaint must make two separate complaints, one to the Privacy Commissioner and another one to HDC. This is not consumer-friendly and takes longer and costs more for no good reason. I recommend changing the Act and Code to let HDC look after the health information privacy parts of complaints about service quality.

RECOMMENDATIONS FOR CHANGE

Summary of recommendations

I recommend that the Health and Disability Commissioner Act 1994 be amended (changed) as follows:

- Change the meaning of “disability services consumer” to make sure it is in line with the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities;
- Change the meaning of “disability services” to add needs assessment and service coordination services;
- Change the sections about the buying of advocacy services to let advocates be staff in HDC;
- Change section 20(1)(c)(i) to widen the “matters of privacy” that the Commissioner can look into under the Code;
- Change the need to look into the Act and Code to every 10 years;
- Add a new section to let information collected during an investigation to be kept private in the Commissioner’s office, while the investigation is still going;
- Replace the phrase “aggrieved person” with the phrase “the complainant (if any) or the aggrieved person (if not the complainant)”;
- Make clear the position of Deputy Commissioners while they are waiting for their reappointment;
- Change the title of section 38 to explain more clearly what it means;
- Increase the fine for an offence under the Act to \$10,000;
- Give expert advisors hired for a short time by HDC the same protection as is given to staff under the Crown Entities Act;
- Make clear that the Director of Proceedings may take action only after a referral from the Commissioner;
- Let the Director of Proceedings make any person give information about a matter before deciding if to issue proceedings.

I recommend that the Code of Health and Disability Services Consumers’ Rights be changed as follows:

- Change Right 4(3) to give disability services consumers the right to access to disability services that they have been assessed as needing after a needs assessment on time;
- Add a definition of “assessed as needing” to clause 4 of the Code;
- Change Right 1(2) to read: “Every consumer has the right to have services provided in a manner that respects the privacy of the individual”, and remove the definition of “privacy” in clause 4 of the Code;
- Change Right 7(4) to read: “It is in the best interests of the consumer or, in the case of research, is not known to be contrary to the best interests of the consumer and has received the approval of an ethics committee”;
- Change Right 7(6)(c) by adding the words: “... or sedation that has a similar effect”.

Disability issues

The Social Services Committee recently looked into the quality of care and service for people with disabilities called **Inquiry into the quality of care and service provision for people with disabilities: Report of the Social Services Committee**, Forty-eighth Parliament (Russell Fairbrother, Chairperson, September 2008) (the Disability Inquiry). The Committee's report has several recommendations on how the quality of care and service could be made better, including:

- having an independent Disability Commissioner (possibly within HDC);
- widening the areas the Commissioner may look into (adding access to disability services); and
- an independent process for checking the funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.

During the Disability Inquiry, HDC raised concerns about the quality of disability services that had shown up in the complaints we receive. Many disability complaints are outside the Commissioner's range of power so he cannot take action. Also, there are often big barriers for people with disabilities to get over before they can make a complaint to HDC. While the Act does let consumers make complaints verbally, disability services consumers don't often complain because they fear punishment, and because there is such a small range and number of disability support services. This is why HDC receives few complaints about disability service provision. In contrast, the advocacy service receives a large number of complaints about disability services and spends a lot of its time on working in the disability sector.

Currently, the Act and Code cover only the quality of services that are given and not how services are accessed or funded. This is a problem as often the way a disability service is funded is the cause of the poor quality service. Complaints about access to disability services, even where quality of service issues are raised, cannot be looked into by HDC. One of the greatest barriers to advocates helping people with disabilities is the amount of their powers, which makes it hard to take a "big picture" approach to helping the consumer.

The reason that consumers and families are often given for providers giving less support is that the funding has gone. Disabled consumers and their families find it hard to get enough information to let them learn the process for needs assessments, reviews and funding. There seems to be a lack of information and good dialogue with disabled consumers about cutbacks and rearranging resources.

Issues of access and funding relating to disability services

Currently, the Act and Code do not cover how services are accessed or funded. The Code only covers the quality of service given. The Act does not say the Code can look into issues of access to services (section 20).

Question 2 in my discussion document asked for suggested changes to the Act and Code about disability, and question 27 asked if there should be any change to the Act about the Commissioner's powers over disability services. In the Disability Inquiry, the Select Committee suggested that the areas a Disability Commissioner could look into should be increased "to include, for example, access to services and individual funding issues". The Commissioner should be "considering disability issues in relation to health, education, social development, and housing, and promoting the recognition that disability is a fact of life and not primarily a health matter" (Disability Inquiry, page 36).

The general theme of feedback was that the Act and Code should be changed to widen the Commissioner's powers over disability services to look into issues of access and funding. Most feedback wanted the Commissioner to be able to look into decisions made about funding for, or access to, disability services:

This lack of access to services **“leads to a feeling of helplessness and loss of independence and self esteem”** for people with disabilities, said the NZ Federation of Business and Professional Women Inc.

People with severe disabilities worry about this as **“their access to and funding of services relates to essential services such as assistance with the necessities of life”** said Judi Strid, Director of Advocacy.

Possible ways suggested in my discussion document for widening HDC's powers about access to disability services include:

- a right for disability services consumers to have the services the consumer has been assessed as needing. This would let the Commissioner look into access decisions only when a needs assessment has been finished and approved;
- letting the Commissioner look into any decision about access to disability services.

The Disability Inquiry recommended the setting up of “an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health”. Much feedback on my discussion document was about widening the Commissioner's powers to link needs assessments made by these organisations to a legal right, so that disability consumers can get the services they have been assessed as needing.

I think that, given the Select Committee's recommendation and the major support in feedback, there is a strong case for legislative change to let the Commissioner check decisions made about access to disability services. I know that concerns about funding and resource allocation decisions may be best dealt with through the accountability of government and funders. I am alert to concerns about the limits on resources, where a provider has a duty under the Code to provide services. However, clause 3 of the Code lets the provider raise the defence of not enough resources to explain why it has not been possible to give a consumer a specific service.

Section 20(2)(a) of the Act permits the Code to provide for anything about the rights of disability services consumers if the Commissioner thinks that the issue is of “particular importance” to disability services consumers. This is a clear signal that Parliament was thinking about broader rights in the disability area. It is clear that access on time to services a disability services consumer has been assessed as needing is really important to disability service consumers.

I recommend that the Code be changed to give disability services consumers the right to access the disability services that they have been assessed as needing after a needs assessment on time. These words should be added to Right 4(3) of the Code: **“Every consumer has the right to have services provided in a manner consistent with his or her needs and, in relation to disability services consumers, to have services that the consumer has been assessed as needing provided in a timely manner.”** A definition of “assessed as needing” will need to be added in clause 4 of the Code, to make sure that the right applies only when a formal, recognised needs assessment has been carried out. I also note that, as said above, clause 3 of the Code has a safeguard for providers who are not able to give the services that a consumer has been assessed as needing because of not enough resources.

Also I think that these other matters are of particular importance for disability services consumers:

- good communication and information from the provider about access decisions and the reasons for accessing services; and
- being part of the process that decides about what services they are to have.

To deal with these matters, I recommend that the meaning of “disability services” in the Act be changed to make clear that needs assessment and service coordination services are disability services.

Definitions relating to disability services

Question 8 in my discussion document asked if the current definitions of disability services are still correct. A lot of feedback said that the definitions of disability services should be brought into line with the definitions used in the New Zealand Disability Strategy and the United Nations Convention on the Rights of People with Disabilities. The New Zealand Disability Strategy states:

“Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.”

The UN Convention on the Rights of People with Disabilities describes disability as:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The Strategy and the UN Convention are powerful documents that came after the HDC Act and Code and today’s disability thinking is in the Strategy and the Convention.

I think that the definitions in the Act should be brought into line with these definitions. I recommend changing the meaning of “disability services consumer” in the Act.

Disability Commissioner

Question 28 of my discussion document asked if a Disability Commissioner looking only at disability issues and services should be created within the Office of the Health and Disability Commissioner (“HDC”). The majority of feedback said that a designated Disability Commissioner should be created within HDC. Two pieces of feedback wanted an independent Disability Commission within the Human Rights Commission, not HDC.

I do not agree with setting up a Commissioner for disability as a separate office. The benefits of having a dedicated Commissioner within HDC include that:

- health and disability are closely linked, and it is fairly common for a complaint to be about both health and disability service providers;
- one of the Deputy Commissioners already looks after disability issues; and
- HDC knows about advocacy and how to sort out complaints for disability consumers.

Section 9(2) of the Act lets the Commissioner give any power, duties or functions to a Deputy Commissioner. Recently, I made one of the Deputy Commissioners “Deputy Health and Disability Commissioner — Disability”. I gave to her the powers, duties and functions of the Commissioner for all disability service investigations.

I do not recommend any change to the Act to make sure a Deputy Commissioner for disability issues is appointed, because the Commissioner’s power to do this is already in section 9(2).

Advocacy services

Currently, the Act sets up an independent advocacy service for health and disability services consumers, which is led by a Director of Health and Disability Services Consumer Advocacy (the Director of Advocacy). The Director of Advocacy is told to work independently of the Commissioner, but reports to the Commissioner for the efficient, effective, and economical management of her activities. This separation of the Director from the Commissioner was meant to protect the advocates’ role in being on the side of the consumer, and the Commissioner’s lack of bias in handling complaints. By their very nature, advocates are not impartial but take the side of, or are biased towards, the consumer. In contrast, the Commissioner must be impartial, unbiased and independent of both consumers and providers when looking into complaints.

After the first review of the Act in 1999, the Commissioner said that advocates should be staff of the Commissioner but keep their duty to act independently, in order to offer a more centralised service. Another ten years of experience has shown again that a change is needed to the structure of the advocacy service. The Director of Advocacy and I both believe the current legal model should be changed to make more certain the effective independent advocacy services for consumers.

Issues with the way advocacy services are organised today include quality assurance and making sure that there is a consistent standard of advocacy services nationwide. The Director has no role in hiring or supervising advocates. There are inefficiencies in the advocacy services — the Director has no direct control over the way money is spent or service is given, and must check on the service through the contract.

Question 5 of my discussion document asked for feedback about the way the advocacy service is organised. Three options were suggested in my discussion document.

Option 1 was to make no change.

Option 2 suggested advocates be HDC staff. This is like the current structure of the Director of Proceedings team. The Director of Proceedings is an independent legal officer who is a staff member of the Commissioner, and leads a small team who are also on HDC staff but report to the Director. The Director of Advocacy would have direct oversight of the quality and consistency of service, and the wise use of resources. The independence of advocacy services would be protected by the law.

Option 3 suggested an independent office of the Director of Advocacy, who would be able to employ advocates directly. This would have the same pluses as Option 2, but it would also give people a feeling of more independence. This option would be more complex as it would likely mean that the Director of Advocacy would be appointed by the Governor-General, rather than by the Commissioner.

In the feedback, of the 46 groups or individuals who answered this question, 32 wanted change. 16 asked for Option 2 and another 16 asked for Option 3, the two options for change.

Feedback about Option 2 said this would be a better use of resources. It would be like the Proceedings model. This would permit the Director of Advocacy to be in charge. This option gives evenness in training and advice. It would make sure the advocates would keep their independence. The advocates would agree to the Public Service Code of Conduct.

“This model provides efficiencies and assurances to the public.” said the National Centre for Health and Law Ethics.

The National Centre for Health and Law Ethics gave the example of the Office of Clients’ Rights Advocacy in California. There, legal advocacy is given by Disability Rights California (“DRA”) through the state-wide Office of Clients’ Rights Advocacy. DRA has legally trained Clients’ Rights Advocates to give independent advocacy, legal advice, and support. These advocates are trained and supervised by DRA but work from within the 24 community-based regional centres. Each regional centre offers assessment and coordination of health, disability, respite and education services for people with disabilities.

The Director of Advocacy supports Option 3 because she believes that is the best way to make sure of the independence of advocates and the Commissioner’s impartiality. The main reason put forward by Option 3 supporters is about greater independence from the Health and Disability Commissioner.

I agree there is a difference between the Director of Proceedings team, which works out of Wellington, and the advocates who work from offices throughout the country. However, in practice, the Director of Advocacy will be in charge of the work of the advocacy service under either Option 2 or Option 3, and supervising this service through an independent office would not be very different from the situation where advocates are staff of HDC.

After thinking about the feedback carefully, I recommend adopting Option 2. This option will help give an even quality of service, with the right duty of care, and it will keep independence from the Commissioner, without the extra cost and complexity of Option 3. It will also reduce administration so that more money can be put into core services and actual service delivery. This recommendation will need several changes to the Act, including the meanings of “advocacy services”, “advocacy services agreement”, and “advocate”, and Part III of the Act.

Review of the Act and Code

The Act tells the Commissioner to regularly look into the Act and the Code to see if any changes are needed, and report what he has found to the Minister of Health (sections 18 and 21 of the Act). This is the third time the Act and Code have been looked at. To date these checks have led to very little change to the original Act and Code.

Question 1 of my discussion document asked if we need to look into the Act and Code every three to five years and if a check once every ten years would be often enough. Fifty-nine pieces of feedback came in about this question; 28 wanted ten-yearly reviews, 16 asked for five-yearly reviews and 15 said no change at all.

I think that the gap between checks of the Act and Code should be increased to at least ten years. The rule to hold such regular checks is not needed. These checks take much time and

money and do not usually bring about much change. No other consumer protection law has such regular reviews. The rule seems to be a hangover from early fears on the part of provider groups that their duties would prove too difficult. If a new problem comes up with the working of the Act or Code (something that becomes less likely as the Commissioner's power is better known over time), discussion may take place on a proposed change, as for any law reform.

I recommend that the Act be changed to say that there should be a check of the Act and Code every ten years.

Definition of “aggrieved person”

The meaning of the term (or words) “aggrieved person” is not explained in the Act. This has caused some court cases. In sections 50 to 58 of the Act, which is about proceedings in front of the Human Rights Review Tribunal (the Tribunal), there is no mention of health or disability services consumer. Instead, the term “aggrieved person” is used.

In the law case Director of Proceedings versus (against) O’Neil [2001] NZAR 59, the High Court said “aggrieved person” covered non-consumers, when the Director claimed damages on behalf of both parents of the baby who had died, where only the mother had been a consumer of midwifery services. The High Court agreed that the parents had a claim under section 57(1)(c) because they were “persons aggrieved” (para 20).

Question 26 of my discussion document asked if the term “aggrieved person” should be explained and should be about just health and disability services consumers. Thirty-one pieces of feedback were made on this question with 22 saying that the term “aggrieved person” should be explained. Within this group, 11 said that the term should be just about health and disability services consumers, and 8 wanted a wider meaning.

Since my discussion document was sent out, the Court of Appeal has ruled, in Marks versus Director of Health and Disability Proceedings [2009] NZCA 151 (28 April 2009), that the term “aggrieved person” in the Act covers only consumers who have rights under the Code. In this case, the Director brought a claim in the Tribunal on behalf of the parents of a man who died because he had harmed himself. The Director asked the Court to say that the Code had been broken by a psychiatrist when giving health services to their son. They also wanted the payment of damages of \$40,000 because of hurt to the feelings of the parents. The central issue was whether the parents were aggrieved persons under the Act.

In deciding that the parents were not “aggrieved persons” under the Act, the Court of Appeal said that it would be hard to work out which people other than actual consumers can be aggrieved persons in any given case. The Court did see two exceptions. Fathers of babies during pregnancy and the birth process may be like consumers and thus aggrieved persons under the HDC Act. Also the Court could see that it would be unfair if a consumer who has died because the Code has been broken was not covered. In such cases executors or administrators would be claiming on behalf of the deceased consumer and not in their own right, and the Court seems to think that such claims are reasonable.

The Court of Appeal has thus made clear the meaning of the terms “aggrieved person” and “person alleged to be aggrieved” in the Act. With the exception of fathers in cases about maternity care, claims before the Tribunal under the Act may only be brought on behalf of consumers. However, there is still the question, would the Act be better if the meaning of “aggrieved person” was widened.

I have looked into two options for change to the definition of “aggrieved person” and access to the Tribunal.

The first option is to define the term as all consumers of health and disability services. This would also add people covered by the meaning of “consumer” in the Code, that is, those who are “entitled to give consent on behalf of that consumer”. A change like this would seem to be enough to allow claims by parents and legal guardians about the care their children receive, and also claims by welfare guardians under the Protection of Personal and Property Rights Act 1988. However, this change would not allow claims by family members of adult consumers who are legally competent to make their own decisions.

The second option uses the Human Rights Act 1993 as a model, removing the words “aggrieved persons” and putting in the words “the complainant (if any) or the aggrieved person (if not the complainant)”, where it appears in relevant provisions from section 51 onwards, notably sections 51–54 and section 57. This option would leave standing the Marks definition of “aggrieved person”, but allow complainants who are not an aggrieved person access to the Tribunal and to awards of damages. Explaining in the law which complainants can bring claims would also not be needed.

After thinking about the options, I prefer option 2. I think that some change to the law is needed because of the Marks decision, which makes access to the Tribunal rather hard. The proposed change would promote accountability and quality improvement, and I believe would not lead to a flood of claims. I recommend changing the Act to adopt the changes suggested in option 2.

The Code

Right to privacy

Currently, the Code does not cover the right to privacy of, and access to, information collected while health and disability services are being given (“health information”). These issues are key parts of the rights of health and disability service consumers, yet HDC cannot fully look into complaints about privacy. Although Right 1(2) of the Code states that every consumer has “the right to have his or her privacy respected”, this right does not cover privacy matters that come under a complaint under the Privacy Act 1993 or the Health Information Privacy Code (see section 20(1)(c)(i)).

The Code can only look after a patient’s physical privacy (such as the place for undressing that makes sure the patient’s privacy is cared for, or the way a provider does a physical examination), and not information privacy. The Commissioner has no power over, and must refer to the Privacy Commissioner, any complaint alleging breach of confidentiality (section 36). This means that a complaint which is about breaking the Code and also about breaking the privacy of information must be split, so that the privacy part is referred to the Privacy Commissioner. This leads to extra effort and works against seeing a complaint as a whole.

Question 4 of my discussion document asked if the Act and Code should be changed to add health information privacy. Forty-seven pieces of feedback were received on this question; 33 supported change and 14 wanted no change. Feedback supported the idea in my discussion document to change section 20(1)(c)(i), taking out the rule that said information privacy could not be covered:

Not only will this let the Commissioner look into cases where privacy has been broken, but it **“will also [allow] low level resolution or disciplinary action to be taken where appropriate,”** said the Nursing Council of New Zealand.

The Privacy Commissioner did not want HDC to look into matters of health information privacy, saying that adding the Health Information Privacy Code into one right in the Code would add confusion rather than make it clearer. She was also worried about different roles looking into health information privacy issues. Other feedback said that the Privacy Commission should be the only agency to consider issues of privacy about health information.

I still believe that there is a strong case for change to put right this missing piece from the Code of Consumers' Rights. The right to privacy of health information is a key part of the quality of health and disability services and the rights of health and disability service consumers. A "one-stop shop" approach, with HDC looking after both the privacy and service quality issues, would be more helpful for complainants and would reduce extra process, time, and expense.

I recommend changing the Act and Code to include health information privacy by changing the meaning of "privacy" in clause 4 of the Code and section 20(1)(c)(i) of the Act to remove the references to the Privacy Act, and amending Right 1(2) of the Code to refer to the right to have services provided in a manner that respects the privacy of the individual.

Informed consent — Right 7(4)

The last time I looked into the Code, I asked if Right 7(4)(a) should be changed to say that services should not be "contrary to the best interests of the patient" because sometimes it is not yet known whether research is in the best interests of the consumer.

Right 7(4) is an important protection for a very at risk group of consumers — those who are not able to give consent and no other person is on hand to give consent for them. Right 7(4) has been very carefully worded to make sure that certain steps are taken before services can be given in these cases.

The first step in Right 7(4) is for the provider to try to get informed consent from someone who is allowed to give consent on the consumer's behalf. Examples of those permitted to consent on the consumer's behalf include a parent giving consent on behalf of a child, or a welfare guardian appointed by the court with power to make health decisions on behalf of the consumer (according to the definition of "consumer" in the Code). If no such person is on hand, the other steps in Right 7(4) must be taken before any service is given.

Right 7(4)(a) then insists the proposed service must be in the best interests of the consumer. This has to be a medical assessment by the provider of the need for treatment. It also must look into the consumer's needs, interests, and quality of life from an all-round point of view, as told by Right 4(4) of the Code. If it is not known that the proposed research or any other service is in the best interests of the consumer, Right 7(4) cannot apply.

Sometimes it is not known in advance if the research is in the best interests of the consumer. The current need to show that the proposed research is in the best interests of the consumer can mean consumers can miss out on the benefit of research that may prove to help them and is known not to be harmful.

In the 2004 review, I asked for a new rule about research on unconscious patients or patients who could not make choices for themselves, with the right safeguards, rather than a total change to Right 7(4) to cover treatment of any kind for patients who could not make choices for themselves. My preferred change to Right 7(4)(a) was to add that, in the case of research,

services may be given when it is not known to be against the best interests of the consumer and the research has been allowed by an ethics committee.

Feedback was almost evenly split (7:8) about changing this right to allow research in some situations on unconscious patients or patients who could not make choices for themselves. Feedback that agreed said yes to the proposed change to Right 7(4)(a) to allow research where it “is not known to be contrary to the best interests of the consumer”. Feedback against the proposed change said that weakening Right 7(4)(a) would increase the risk for, and reduce the protection of consumer rights for, an already very at risk group of health consumers.

In asking for this change, I knew that these are a very at risk class of consumers, and care needs to be taken to make sure that general protection of them is not reduced. However, it must be noted that Rights 7(4)(b) and (c) impose extra safeguards, telling the provider to also take steps to find out what the consumer would want if he or she were able to decide. Services may only be given where they are in line with the informed choice the consumer would make if he or she could make that choice. Where it is not possible to find out this information, the views of other “suitable persons” able to advise the provider must be thought about. “Suitable persons” may be family, partners, friends or caregivers who have an interest in, and a relationship with, the consumer such that it makes them suitable advisors on the type of care they believe is in the consumer’s best interests.

Therefore, I recommend that Right 7(4)(a) of the Code be changed to read:

“It is in the best interests of the consumer or, in the case of research, is not known to be contrary to the best interests of the consumer and has received the approval of an ethics committee.”

Written consent — Right 7(6)

Right 7(6) says that where informed consent to a health care procedure is needed, it must be given in writing if:

- (a) the consumer is to be a part of any research; or
- (b) the procedure is experimental; or
- (c) the consumer will be under a general anaesthetic; or
- (d) there is a high risk of bad effects on the consumer.

One piece of feedback said that the term “general anaesthetic” is not a clear term as there are several drugs that can put the patient to sleep that are quite similar to a general anaesthetic. This advice came from Dr Colin McArthur, Clinical Director, Dept of Critical Care Medicine & Medical Advisor — Quality and Safety, Auckland DHB.

I agree that the term “general anaesthetic” needs to be made clear and I recommend changing Right 7(6)(c) to add the words “... or sedation that has a similar effect”.

Administrative amendments

Status of Deputy Commissioners pending reappointment

The Ministry of Health has asked that the Act is made clearer about reappointment of Deputy Commissioners because it is not clear how to look after their positions while waiting for their reappointment.

Question 10 of my discussion document asked if there was support for making clearer the situation of Deputy Commissioners pending reappointment. Thirty-five pieces of feedback came in about this question and all supported a change to make clearer the situation for the Deputy Commissioners.

Given the support for this change, I suggest a change that would make HDC more like the Privacy Commissioner's office. I recommend changing the Act by inserting a subsection in section 9 of the Act stating: "Part 2 of the Crown Entities Act 2004, except section 46, applies to the appointment and removal of a Deputy Commissioner in the same manner as it applies to the appointment and removal of a Commissioner."

Decision to "take no action" — section 38

The Act lets the Commissioner decide to take no action if the Commissioner thinks that, having looked at all the facts of the case, no action is needed (section 38(1)). Under section 38(4), the Act tells the Commissioner to give the complainant and the provider the reasons why he is taking no action on a complaint.

The things that the Commissioner may think about when deciding not to take any action are spelt out in section 38(2), for example that:

- the consumer wishes no action to be taken;
- the complaint is trivial or is not made in good faith; or
- a way of sorting out the complaint or right of appeal is already there.

Usually, before the Commissioner decides to take no further action on a complaint, he asks for and thinks about a lot of information, and he may also get expert medical advice. Most complaints decided under this section of the Act are where HDC thinks a teaching approach is better than an investigation. Mostly HDC gets an apology and makes sure of follow-up action by the provider(s). Section 38 is also used because matters are already being sorted out through other better ways or other agencies are helping.

Question 13 of my discussion document asked if section 38 should be changed to better explain what it does. Thirty-six pieces of feedback were made on this question, with 26 asking for a change. Of those in favour, six suggested change to the title of section 38.

I think the heading "Commissioner may decide to take no action on a complaint" is misleading, because this decision is only ever taken after carefully getting and thinking about information. I recommend changing the title of section 38 to read: "Commissioner may decide to take no further action on a complaint".

Withholding information obtained during investigations

At the moment, HDC has to obey the rules of the Privacy Act 1993 and the Official Information Act 1982 (the OIA). This means that HDC must look into every request for information held by the Office to decide if giving out that information is in line with the laws. This is a hard task that takes time. Giving out information during an investigation helps providers who know more about HDC's processes during an investigation and may seek to benefit from having this information.

Question 19 of my discussion document asked if the Act should be changed to allow information that has come in during an investigation to be kept private by the Commissioner, while the investigation is going on. Most feedback was in favour of this change (33 out of 41

pieces of feedback). The Privacy Commissioner said that HDC should have a similar power to the Privacy Commissioner's office to keep private any information that has come in during an investigation while the investigation is going on, as this is a real safeguard for the honesty of a complaint investigation process.

I believe the Act should be changed to allow information that has come in during an investigation to be kept private by the Commissioner, while the investigation is going on, to allow speedy and efficient investigations. This issue was discussed during the 1999 review, when the Commissioner recommended that a new section should be added into the Act allowing HDC to keep secret material that has come in during an investigation (but keeping the option to give out material where this is necessary to give proper effect to the Act). As noted above, the Privacy Commissioner, as an equal legal body, has a similar provision. Section 55(e) of the Privacy Act 1993 states that the right to request access to personal information does not apply in respect of "Information contained in any correspondence or communication that has taken place between the office of the Commissioner and any agency and that relates to any investigation conducted by the Commissioner under this Act, other than information that came into existence before the commencement of that investigation". Putting a similar rule in the HDC Act would not risk the fairness of the investigation. All relevant information would continue to be given out to the people who need to know when the Commissioner makes a provisional decision, to follow the rules of natural justice.

I recommend that a new section be added to the Act to allow information that has come in during an investigation to be kept private by the Commissioner, while the investigation is going on.

Offences — section 73

Section 73 says that every person commits an offence against this Act and is liable if found guilty to a fine of not more than \$3,000 who:

- (a) Without a good reason, gets in the way of or stops the Commissioner or any other person from doing their work under this Act;
- (b) Without a good reason, does not obey any lawful instruction from the Commissioner or any other person under this Act;
- (c) Says anything or gives any information to the Commissioner or any other person working under this Act, knowing that the words or information are false or misleading; or
- (d) Claims in any way that he or she has any power under this Act when he or she does not have that power.

Question 16 of my discussion document asked if the maximum fine should be increased from \$3,000 to \$10,000. Forty-four pieces of feedback came in, with 33 in support of increasing the fines.

I believe the \$3,000 maximum fine is very low for the offences covered and does not warn people off who get in the way of the Commissioner's work. I support a change to increase the fine for an offence under the Act to \$10,000. This is like the Health Practitioners Competence Assurance Act 2003 (section 172, \$10,000 fine) and other consumer protection legislation (Fair Trading Act 1986, section 40, \$10,000 fine).

Immunity for independent expert advisors

Sections 120 to 126 of the Crown Entities Act 2004 give some protection from being sued to "members, office holders or employees" of statutory entities so long as what they actually did

do was “in good faith and in performance or intended performance of the entity’s functions”. Before the Crown Entities Act came into law, independent expert advisors hired to work for the Commissioner were protected by section 65(2)(a) of the Act. However, as independent advisors are not “members, office holders or employees”, the protections in the Crown Entities Act cannot be used by them.

Question 18 of my discussion document asked if the Act should be changed to give independent expert advisors hired by HDC the same protection from being sued given to “members, office holders or employees” under the Crown Entities Act. Thirty-nine pieces of feedback were made on this question and 31 wanted such a change.

I noted in my discussion document that the risk of independent advisors being legally challenged is very low. However, I believe that the Act should be changed to give expert advisors hired by HDC the same protection from being sued given to “members, office holders or employees” under the Crown Entities Act. I recommend changing section 65(1) to include “any person engaged in connection with the work of the Commissioner”.

Director of Proceedings

Action upon referral — section 47

The Director of Proceedings has pointed out that section 14(1)(f) of the Act does not say that the Commissioner must have finished an investigation before referring a provider to the Director of Proceedings. The Director of Proceedings has recommended change to sections 47 and 14(1) of the Act to make it clear that any powers or functions of the Director can be used only after referral from the Commissioner after an investigation (that is, referral in line with section 45(2)(f)).

From time to time a complainant has gone straight to the Director for assistance or representation where there has been no referral by the Commissioner. Because section 47 comes before section 49, it is not surprising that there has been a belief that the Director may act without a referral. However, the Director has not taken any action in such proceedings, on the basis that a referral from the Commissioner is needed before the Director can use the powers and functions under section 49 of the Act. It is clear from the later parts of the Act that there must be an investigation before referral.

Question 21 of my discussion document asked if section 47 should be changed to make it clear that the Director of Proceedings may take action only after a referral from the Commissioner. Thirty-four pieces of feedback were made and 30 agreed with the proposed change.

I recommend that section 47 be changed to make clear that the Director of Proceedings may take action only after referral from the Commissioner.

Same power as Commissioner to require information

In the time from referral to the Director of Proceedings until a charge or statement of claim is filed, there is no power for the Director to make the people or groups concerned hand over information. Section 62 gives the Commissioner the power to have information handed over that is important for the investigation. The Commissioner can also insist that a person can meet him and speak to him under oath, just like being in court.

The Director of Proceedings has no power to do this. The referral to the Director takes place once the investigation by the Commissioner has been finished and, because the Director's powers and functions are carried out independently and separate from the Commissioner, the Commissioner is no longer a part of the matter.

Once a charge has been laid, the tribunals may call for information on the request of a party to the case. However, sometimes the Director may wish to get extra information to decide, under section 49, what (if any) action to take in the first place. In particular, the Director may think a specific piece of information is very important in deciding whether to lay a disciplinary charge against a provider.

Question 22 of my discussion document asked if the Director of Proceedings should have the same power as the Commissioner under section 62 to call for information, until a decision has been made under section 49 to issue any proceedings. Thirty pieces of feedback were made on this question and 26 agreed with the proposed change.

I recommend that section 49 be changed to add new powers for the Director of Proceedings to get information about a matter being thought through until a decision has been made to issue proceedings.

ISSUES NOT REQUIRING CHANGE

The Act

Definitions of health services

Many different opinions were given on changes to the definitions in the Act about health services. Several pieces of feedback asked for the definitions to be made simpler and clearer. Others wanted no changes to the definitions.

I think there is no strong reason for any change to these definitions at this stage.

Health and Disability Commission

During the 2004 review of the Act, there was talk about changing the name of Office of the Health and Disability Commissioner to the “Health and Disability Commission”. Use of the term “Health and Disability Commissioner” in a letter or a report, and referring also to the legal body (Office of the Health and Disability Commissioner) in contrast to the individual office-holder, is often clumsy.

Most feedback supported this change: of 48 pieces of feedback, 44 were in support of a change of name to the “Health and Disability Commission”. Even so, I worry about the practicalities and costs of this change.

Therefore I do not recommend any change to the legislation.

Commissioner’s functions

While several pieces of feedback asked for more functions for the Commissioner, many believed that the Commissioner’s current functions set out in the Act are right.

None of the feedback asking to broaden the functions of the Commissioner convinced me that any change to the Act is necessary.

Requirement to refer all complaints to the relevant registration authority

Feedback for and against whether the Commissioner should be told to refer all complaints about registered health practitioners to the relevant registration authority was evenly split (23 said yes, 21 said no). I think the current referral system is good. My office has written agreements with a number of registration authorities and these authorities are informed of complaints in cases where we think this should happen.

I recommend that no change be made to the Act on this issue.

Right of appeal

Some provider groups suggested that providers should have a right of appeal from a Commissioner’s opinion where a provider has been found to have broken the Code or when a provider’s name has been told to the public because the provider has been found to have broken the Code. Most pieces of feedback pointed out that the HDC Act says the Commissioner’s decisions can be looked into by the Ombudsmen or a judicial review can be called for.

I agree and recommend that no appeal right be added to the Act.

Naming of providers

Some feedback said that the Act should be changed to allow the Commissioner to name providers found to have broken the Code. However, more feedback opposed such a change. HDC's naming policy sets out the factors that are thought about when making a decision to name a provider. The parties are given a chance to comment before the decision is finalised. I believe HDC's current naming policy is working well and I do not think it is necessary to give another way to appeal a naming decision.

Only a little feedback supported a change to let the Commissioner suppress identifying information during an investigation and afterwards when no breach has been found.

I do not believe a change is needed on this issue.

Ethics committees

Most feedback thought that ethics committees should not come under the oversight of HDC because of the worry that this might risk HDC's independence. Two pieces of feedback were worried that the rights of those who took part in research were being put at risk and should be protected by HDC. Others thought that a separate Director of Ethics within HDC would answer the concern about independence. The Ministry of Health has advised that it is currently looking into all things about ethics committees.

I recommend that no change be made about ethics committees at this stage.

Complainants commenting on Commissioner's provisional (draft) opinion

Feedback was evenly split about giving complainants the chance to comment on the Commissioner's draft opinion (19:19). The speediness of an investigation must be balanced against the need for natural justice and fairness to the providers being looked into. I agree with the point made in one submission that giving out the Commissioner's draft opinion could risk information getting out into the media. Draft opinions sometimes change a lot before the final finding.

I am not convinced by feedback that a change to the Act is necessary on this issue.

Timeframes for investigations

Very few pieces of feedback came in about the Act needing to have timeframes for the Commissioner's investigations (3 were in favour of a timeframe, 5 against). HDC always tries to finish investigations in a "speedy and efficient" manner. Most investigations are completed within 12 months (with a handful taking 18–23 months).

I believe it is not necessary to state a timeframe for investigations in the Act. I recommend that no change be made.

Limitation period

For some years now the Law Commission has been looking into and discussing change to the Limitation Act 1950, which limits the time between a bad event taking place and when the

bad event can be taken to a court of law. During the discussion process, the Director of Proceedings recommended that the HDC Act be changed to provide for a period of limitation about Human Rights Review Tribunal proceedings, with the limitation period starting at the time the Commissioner finds that the Code has been broken. This is because no one has the right to bring proceedings until there has been a breach finding. This is quite different from any other person or organisation who wishes to use the protection of law through the courts, who can bring a claim in a court as soon as the bad event occurs.

Most feedback on this issue agreed that any limitation period under the Limitation Act should start to run from the date on which the Commissioner finds the Code has been broken (29 in total with 26 in support of the proposed change).

Since the feedback period finished, a Limitation Bill has been introduced into the Parliament (on 2 June 2009). Given that the Limitation Bill is going through the legislative process, and does not specify a limitation period for claims made in proceedings in the Human Rights Review Tribunal, I do not suggest any change to the HDC Act at this time.

The Code

Right to access publicly funded services

The Act does not cover which services are to be funded by public funds. The Act is about the quality of services that are given. Section 20 talks about only the quality of service given and does not let the Code cover access to health services.

A right to access health services was thought about during discussions about the original Code, and in the two later reviews. Even though there was feedback in support of this right, neither report on the reviews recommended changing the Act and Code to include a right of access to services.

Question 3 in my discussion document asked if the Act and/or the Code should be changed to add a right to access publicly funded services. Fifty-one pieces of feedback came in about this question, with 15 wanting no change and 36 wanting a right to access publicly funded services.

Those in favour talked about the issue of equity of access for all consumers:

“FWHC supports national equity of access to publicly funded services so that patients have similar access regardless of where they live, their socio-economic or cultural status, or any other perceived barriers, including disability,” said the Federation of Women’s Health Councils Aotearoa.

A few suggested that the right be only the right to access services in a “timely manner”, or “the right to access timely and appropriate services”. One suggested a change based on Scottish public service reforms, “the right to access convenient and appropriate public services” (Public Health South).

I know that access and funding issues are not easily looked into by the courts. Feedback against this change raised the same concern:

“Decisions regarding access involve complex resource allocation issues which should generally be left to the government, rather than enforced through the Code of Rights,” said the NZ Private Surgical Hospitals Association Inc.

However, clause 3 of the Code would let providers put up a defence about why it has not been possible to meet a particular consumer's right to access a particular service. In my discussion document, I suggested the possibility of some form of limited right to access services, without opening the door fully to the rights to access services generally.

After thinking a great deal about the feedback, I believe the Code should not have a limited right to access publicly funded health services. In contrast to the limited right to timely access to disability services discussed above (page 3), a right to access publicly funded health services would be open-ended and would draw the Commissioner into rationing and prioritisation issues which live with government and funders.

Compassion

The Centre for Compassion in Healthcare (the Centre) said that the Code should be changed to add a "right to be treated with compassion". The Centre noted the link between compassion and patient safety, the emotional impact of the health care experience, and the importance of having standards in law that align with the core values of health care. In the United Kingdom, the new NHS Constitution has "compassion" as a core value of the NHS (but not a right, in contrast to "respect" and "dignity"). The quality of compassionate caring shown by every nurse in the NHS is to be measured by patient feedback (see <http://news.bbc.co.uk/1/hi/health/7460720.stm>).

The Centre suggested changing Right 1(1) of the Code to read: "Every consumer has the right to be treated with compassion and respect", and adding a clause to Right 1 to read: "Every consumer has the right to have services provided with compassion, including a prompt and humane response to distress, pain and suffering."

Most feedback on the proposal was in favour of this change (44:19). Also a petition came in from the Centre with 529 electronic signatories in support of adding the right to be treated with compassion to the Code.

"Compassion is defined as the humane quality of understanding suffering in others and wanting to do something about it," said the Centre for Compassion in Healthcare.

The Centre said that adding the right to be treated with compassion is based on the belief that the current Code does not have such a right. In the Centre's view, the words "respect" and "dignity and independence" do not show the meaning and purpose of compassion well enough, and so this needs to be stated as a right in the Code.

Most feedback in favour of this change suggested that Right 1(1) be altered to state that "Every consumer has the right to be treated with compassion and respect". Many echoed the Centre's concern that the current wording of the Code does not have in it the idea of compassion. The Quality Improvement Committee said:

"Committee members argued that compassion has a meaning distinct from dignity and respect, as it relates particularly to the humane understanding and relief of suffering in people who are very vulnerable. While there are undoubtedly many deeply compassionate health professionals, sometimes our systems of care allow consumers to suffer unnecessarily through neglect of basic human needs. Adding a right to be treated with compassion will strengthen the ability of the Health and Disability Commissioner to address institutional neglect of consumers' basic needs".

Feedback against adding a right to compassion to the Code said that the current wording in Right 1 already covers “compassion”, and that any right that insists on a certain “emotion” could not work.

In reply, the Centre says that the test of the Code is in the “breach”, and lack of compassion is usually obvious because an ordinary person would judge that the consumer has suffered unnecessarily. Compassionate care can also be judged by the experience of the consumer and his or her family, the experience of loving kindness, and the relief of pain, suffering and fear.

Those against adding compassion said that it would be very hard for the Commissioner to measure an emotion or feeling of compassion and to decide if a provider is actually feeling compassion.

On 11 June 2009, I held a national meeting to discuss this issue further with 20 key stakeholders and people who gave detailed feedback about a right to compassion. Everyone present agreed that compassion is an important virtue in health care, and many shared a sense that it is often missing, especially in hospital settings. Those in favour said that the Code is a “living document”, that in the 21st century an ethic of “care” fits with the earlier emphasis on autonomy, and that the proposed right would call on the force of the law to change attitudes and behaviours.

However, those at the meeting also saw that the use of compassion for disability services is not appropriate. Disability service consumers do not want to be thought of as suffering and needing to have something done “to” them. DPA New Zealand gave powerful feedback explaining this concern. DPA said they would strongly go against such a change and they urged the Commissioner to use different non-Code ways to emphasise compassion.

Having thought about this, I agree that adding the proposed right would reduce the confidence of disability services consumers in the Code because “treatment” with “compassion” is a type of care that is not correct in a disability context. I appreciate the concern about the absence of compassion in health settings, and I support moves to urge compassion in health care. However, I do not believe that the law is the most effective way to promote a virtue, and I have some doubt about making a legal duty to be compassionate work. What’s more, the Code is already broad enough to denounce neglectful and callous conduct (see, eg, case 05HDC11908, 22 March 2007).

I believe the very good goal of compassionate health care is better looked after by ethics and training than by rules in law. Where the law can play a role, I prefer to focus on a provider’s duty of care under Right 4 of the Code. Where professional ethical statements include a duty to act compassionately, Right 4(2) gives consumers the right to compliance with that “ethical standard”.

There is also room to make more use of Right 4(3) (a consumer’s right to have services provided in a manner consistent with his or her needs) and Right 4(4) (a consumer’s right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer). The clause 4 definition of “optimise the quality of life” — “to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances” — is broad enough to cover the prompt and humane answer to distress, pain and suffering.

For these reasons, I do not recommend that a right to be treated with compassion be added to the Code.

Right to effective communication — Right 5

Much feedback on Right 5 of the Code supported a national interpreting and translation service being made available through HDC. While I support a national interpreting service, the Commissioner's office and the Director of Advocacy do not have funding to pay for such a service, and it would have to go beyond health and disability services (for example, to cover social services and education). Such a broad service is beyond the scope of HDC. I do, however, support a national approach to interpreting and translation services to make sure that the right to effective communication (and informed consent) can be used.

I recommend that no change be made to the Code to provide a national interpreting and translation service.

Written consent — Right 7(6)

Some feedback came in about Right 7(6), and most supported looking at the rules for written consent under the Code. The issue raised was that the Code seems to insist on written consent for the prescription of medicine. This has not been a problem over the past 13 years.

I believe a commonsense approach must be taken to knowing what the Code means here. I do not think that any change should be made to the Code about this part of written consent.

Consent to the storage, preservation or use of body parts or substances - Right 7(10)

A number of pieces of feedback came in calling for changing back the 2003 change of Right 7(10). However, the same number of pieces of feedback supported the right as it is currently worded, as it has allowed valuable research.

Given that, in practice, the exemptions from the informed consent rules under Right 7(10) apply in very limited situations, I recommend that no change be made to Right 7(10).

APPENDIX A — CONSULTATION PROCESS

Section 18 of the Health and Disability Commissioner Act governs the procedure for review of the Act. Unlike the rules about review of the Code, there is no rule for discussion, apart from the general rule to discuss with providers and consumers in section 14(2).

Section 22 (incorporated by section 21(3)) and section 23 of the Act set out the discussion rules for review of the Code. As the reviews of the Act and Code happened at the same time, the same broad discussion process was carried out for both.

Consultation process

In August 2008, we wrote to representative persons and organisations with an interest in health and disability service matters, including consumers, providers, and statutory agencies, asking for their first thoughts on the review.

Thinking about what they said and adding my own thoughts about the Act and Code, I put out a discussion document and asked the public what they thought in November 2008. My discussion document talked about a wide range of issues. Several key parts in the Act and Code were raised to seek feedback. Where appropriate, I gave my first thoughts on where the Act and Code would be helped by change.

Feedback was asked for again from interested organisations and individuals, as well as from the public at large. Two hundred and ninety-nine copies of my discussion document were posted and sent electronically. The HDC free phone 0800 number was available for those wishing to request information or to give their feedback verbally. My discussion document was also posted on the HDC website and received approximately 2,500 hits during the feedback period (November 2008–February 2009).

One hundred and twenty-two pieces of feedback (submissions) came in as an answer to my discussion document. The feedback was thought about carefully and analysed. An analysis of the feedback is in Appendix C.

In the discussion document, we suggested having public meetings if people were interested. However, due to a lack of interest in such meetings, we did not hold public meetings. But, in answer to requests, we did hold two forums in Auckland in January and February 2009 focusing on the possible changes about disability services consumers' rights, at the request of Auckland Disability Law and Deaf Aotearoa New Zealand. Also we held a meeting with those who talked about the proposed right to be treated with compassion in June 2009. Feedback on the Act and Code and proposed changes was received during these meetings.

APPENDIX B — LIST OF SUBMISSIONS

	Submission No.
A W Beasley	49
Age Concern New Zealand	41
AIDS Epidemiology Group, University of Otago	22
Ann Bain	47
Annie Price	25
Auckland Deaf Christian Fellowship	98
Auckland Disability Law	117
Auckland Disability Providers Network Inc	106
Auckland Women's Health Council	64
Australian and New Zealand College of Anaesthetists, NZ National Committee	88
Bay of Plenty DHB	36
Brain Injury Association of Auckland	79
Cancer Society Tissue Bank, Christchurch	1
Canterbury DHB Consumer Advisors	62
Canterbury Mental Health Consumers Network	89
Capital & Coast DHB	112
Carol McCord	11
Catherine Gibson	8
CCS Disability Action	59
Centre for Compassion in Healthcare	68
Complex Carers Group	51
David Loving-Molloy	29
Deaf Aotearoa New Zealand	75
Disabilities Resource Centre Trust	103
Disability Information Waitakere Network	70
Dr Colin McArthur	97
Dr Elizabeth Harding	61
Dr Evan Mason	13
Dr Nigel Millar	3
Edel Felix	10
Equity for Illness	21
Family Planning	101
Federation of Women's Health Councils Aotearoa	91
Gail Lyons	26
Gary Watts	12
Geoff Cardwell	50
Health Research Council of New Zealand	120
HealthCare Providers New Zealand	24
Helen Capel, Suzanne Paul and Graham Foster	92
Helen Morrin	99
Hine Potaka	18
Human Rights Commission	113

IHC	84
Jacqueline Raynes	28
Jacquie Kerslake	31
Jane Cunningham	27
Jenny Miles	19
Jill Lamb	17
Judi Strid, Director of Advocacy	116
Julie Hermes	6
Kathy Torpie	4
Katrina Fowler	2
Katrina Strickett	63
Kites Trust	85
Leo Hobbis	7
Lorna Dyall	100
Manawanui Ariki Charitable Trust, Generation 9	95
Margaret O'Sullivan	9
Marion Partington	23
Maternity Services Consumer Council	87
Medical Council of New Zealand	58
Mental Health Commission	57
Mental Health Foundation of New Zealand and Mental Health Advocacy Coalition	67
Ministry of Health	119
Muscular Dystrophy Association of New Zealand Inc	78
Name withheld	107
Name withheld	71
Name withheld	96
National Advocacy Service Managers Group	104
National Centre for Health Law and Ethics	74
National Council of Women of New Zealand	53
Nationwide Advocacy Trust	60
New Zealand Association of Optometrists Inc	105
New Zealand College of Midwives	81
New Zealand Council of Christian Social Services	108
New Zealand Federation of Business and Professional Women Inc	33
New Zealand Medical Association	40
New Zealand Nurses Organisation	55
New Zealand Organisation for Rare Disorders	32
New Zealand Private Surgical Hospitals Association Inc	43
New Zealand Psychologists Board	46
New Zealand Sterile Services Association	35
Nigel Dunlop	20
Nursing Council of New Zealand	122
NZRDA and New Zealand Medical Professionals Ltd	82
Osteopathic Council of New Zealand	80
Otago and Southland DHB	114
P S Survivors Inc	44

Palmerston North Women’s Health Collective	52
Peter Kimble	5
Pharmac	102
Pharmaceutical Society of New Zealand Inc	93
Pharmacy Council of New Zealand	90
Privacy Commissioner	42
Professor George Salmond	14
Professor Grant Gillett	16
Professor Peter Skegg	69
Public Health South	115
Quality Improvement Committee (QIC)	48
Rachel Coppage	30
Rescare New Zealand Inc	94
Robert Finlay	37
Royal Australasian College of Physicians	109
Royal Australasian College of Surgeons	110
Royal Australian and New Zealand College of Psychiatrists	86
Royal New Zealand Foundation for the Blind	38
Royal New Zealand Plunket Society	65
Rural Women New Zealand	66
Sacha Dylan	118
Sarah Hunter	45
Stuart McLennan ¹	56
Taranaki DHB	54
Te Puni Kōkiri	73
Te Roopu Taurima O Manukau Trust	39
The New Zealand Committee of Pathologists, RCPA	72
The Royal New Zealand College of General Practitioners	111
Tina Smith	15
Wairarapa DHB	77
Waitaki District Council, Positive Ageing Working Party	34
Wakefield Health Limited	121
Wilson Home Trust	76
Women’s Health Action Trust	83

¹ Stuart McLennan is employed by HDC but submitted in his personal capacity.

APPENDIX C — ANALYSIS OF SUBMISSIONS

This appendix goes through the questions asked in my discussion document for the Review of the Act and Code (November 2008), which you can find at www.hdc.org.nz. This appendix looks at each theme or topic and explains in detail the feedback that came in about each theme. Each piece of feedback is linked back to the name of the person or organisation who gave it.

To read about all this feedback, please go to the full version of this report, pages 29–45.

APPENDIX D — DRAFTING FOR RECOMMENDED CHANGES TO THE ACT AND CODE

To make my recommendations clear, I have set out suggested legal drafting for the recommended changes to the Act and Code.

From here until the end of the report are the legal words that Parliament will need to make the changes. If you would like to look at this legal language, please go to the full version of this report, pages 46–52.